I. Introduction

1. The present study was prepared in consultation with indigenous persons with disabilities. In this regard, an expert meeting was held in Madrid on 20 and 21 November 2012, bringing together indigenous persons with disabilities from various regions and other experts, including from the United Nations, working in the areas of indigenous peoples and persons with disabilities.

2. The *World Report on Disability*, produced by the World Health Organization and the World Bank in 2011, estimates that 15 per cent of the world's population has a disability, of whom 3 per cent has a severe disability. Applying this percentage to the estimated 360 million indigenous persons, the number of indigenous persons with disabilities stands at approximately 54 million.

3. The lack of reliable data is a problem both for indigenous peoples and for persons with disabilities, given that very few countries have statistics on indigenous persons with disabilities. Data from Latin America and Australia provide a diverse picture. In some countries, the prevalence of disability among indigenous persons is lower than in the general population, whereas it is much higher in others.

4. In Latin America, available statistics for seven countries (Brazil, Colombia, Costa Rica, Ecuador, Mexico, Panama and Uruguay) show that there is a higher rate of disability among indigenous persons than the rest of the population. In Brazil and Colombia, however, the rate is lower among indigenous children. For persons aged 19 and older, there are more indigenous persons with disabilities than non-indigenous for all seven countries, with sizeable gaps in Costa Rica and Uruguay.

5. In Australia, about half of indigenous adults reported a disability in 2008,[2] as compared with a national figure of 18.5 per cent in 2009 gathered through a survey of disability, ageing and carers. In New Zealand, statistics were published in 2006 on disability and Maori. A disability survey found, after adjusting for the age structures of the two populations, that the age-standardized disability rate for Maori was 19 per cent, compared with 13 per cent for non-Maori. More Maori persons with disabilities are living in poverty or have no educational achievements, as compared with non-Maori persons with disabilities.[3]

6. In Canada, some statistics have been provided on aboriginal persons with disabilities by state and by indigenous people. In 2000, the observer for Canada informed the Working Group on Indigenous Populations that aboriginal children were three times more likely than non-indigenous children to have physical disabilities (E/CN.4/Sub.2/2000/24, para. 34). A First Nations regional longitudinal health survey conducted in 2002/03 provided some information about prevalence, employment, education, income and health status, in addition to making recommendations. The survey showed that about 22.9 per cent of on-reserve persons aged 18 and over had disabilities.

7. There are a number of reasons why disability would be more prevalent among indigenous peoples than among the general population, including higher levels of poverty, increased exposure to environmental degradation, the impact of large projects such as dams or mining activities and the higher risk of being victims of

[2] See www.healthinfonet.ecu.edu.au/health-facts/overviews/disability.

[3] Office for Disability Issues and Statistics New Zealand, *Disability and Maori in New Zealand in 2006: Results from the New Zealand Disability Survey* (Wellington, Statistics New Zealand, 2010).

violence. The 2009 edition of the *State of the World's Indigenous Peoples* report mentions, in particular, mental health issues and the prevalence of diabetes among indigenous persons.[4]

8. While data on the prevalence of disability among indigenous peoples are important, it is even more important to have information on the actual well-being and inclusion of indigenous peoples. Accordingly, the situation of indigenous persons with disabilities must be taken into account in efforts to develop new statistical tools that will reflect the situation of indigenous peoples in a culturally sensitive way, as outlined in the *State of the World's Indigenous Peoples* report.

Legal framework

9. Two international instruments provide the main legal, conceptual and political framework for the protection and promotion of the rights of indigenous persons with disabilities. Articles 21 and 22 of the United Nations Declaration on the Rights of Indigenous Peoples make specific reference to persons with disabilities. The Convention on the Rights of Persons with Disabilities, which following its entry into force in 2008, now has 127 States parties, includes a single reference to indigenous peoples in its preamble.

10. The Convention, as other human rights treaties, focuses primarily on individual rights, but also contains provisions of a more collective nature. The approach of the Declaration is primarily collective, but also includes references that provide individual rights. Both instruments have in common their comprehensive nature and, while both would have benefited from more explicit references to indigenous persons with disabilities, read together, they provide useful guidance to States, indigenous peoples and other stakeholders.

11. The Convention provides detailed guidance on how States are to promote and protect the rights of persons with disabilities, which clearly includes indigenous persons with disabilities. Implementing the Convention in a way that also respects the Declaration means that, whenever relevant, the measures foreseen in the Convention will need to be applied in a way that is sensitive to the culture and world vision of indigenous peoples in order to best protect the rights of indigenous persons with disabilities.

12. While legislation and policies designed for persons with disabilities often have the objective of ensuring the full inclusion of those persons in mainstream society, indigenous peoples tend to be wary of any form of mainstreaming that may lead to assimilation and threaten their languages, ways of life and identities. For indigenous persons with disabilities, whether living in their communities and/or in urban settings where indigenous institutions may be located, this distrust should result in ensuring that indigenous persons with disabilities are supported to fully take part in the life of their communities.

13. Another important instrument is the Convention concerning Indigenous and Tribal Peoples in Independent Countries (Convention No. 169), under the auspices of the International Labour Organization, which recognizes, in the fourth preambular paragraph, that there is a need to remove the assimilationist orientation

[4] *State of the World's Indigenous Peoples* (United Nations publication, Sales No. E.09.VI.13), pp. 163 and 169-172.

of earlier standards and acknowledges other important developments such as the rights to culture and land. Implementing this instrument includes consultations, respect for customs and agreement with international human rights law.[5]

14. There appears to be little awareness among indigenous persons with disabilities of the Declaration and the Convention on the Rights of Persons with Disabilities. The Declaration is available in a number of indigenous languages, unlike the Convention. Translation, dissemination and a process of appropriation by indigenous peoples of the Convention are needed.

Purposeful absence of prevention of disability in the Convention

15. The negotiators of the Convention purposely did not include the issue of prevention of disability except in article 25, on health, in relation to preventing further disabilities for persons who already have a disability. Because the Convention deals with persons who already have disabilities, it follows that legislation and policies targeting the rights of persons with disabilities should avoid addressing the issue of prevention of disability. In addition, discussions around prevention often perpetuate negative, discriminatory and harmful stereotypes about disability. The greater chances in some indigenous communities of acquiring a disability (including those more closely linked with poverty, environmental contamination or working conditions), can, however, be discussed under the auspices of other relevant frameworks and not when discussing the rights of persons with disabilities (and keeping in mind the need to avoid harmful stereotypes about disability). If there are disproportionately more persons with disabilities among indigenous peoples, as compared with the rest of the population, this could be relevant in evaluating whether and how well any necessary services and support for persons with disabilities are provided by relevant parties. For these reasons, and using the Convention as a reference, prevention of disability is not discussed herein.

II. Attention by the United Nations to indigenous persons with disabilities

16. Indigenous persons with disabilities have been largely invisible in the work of the various United Nations entities that address the rights and situation of indigenous peoples and persons with disabilities. The *World Report on Disability* includes very little information on indigenous persons with disabilities, while the *State of the World's Indigenous Peoples* report notes only that indigenous persons are more likely to have a disability, including mental health issues leading to higher suicide rates. The Expert Mechanism on the Rights of Indigenous People and the Special Rapporteur on the rights of indigenous peoples have to date not addressed the specific situation of indigenous persons with disabilities.

17. Of the 27 States that have submitted their first periodic reports to the Committee on the Rights of Persons with Disabilities to date, 10 have mentioned indigenous peoples: Argentina, Australia, Cook Islands, Costa Rica, Denmark, Kenya, Mexico, New Zealand, Paraguay and Peru. Some references to indigenous

[5] See John B. Henriksen, "Key principles in implementing ILO Convention No. 169", Research on Best Practices for the Implementation of the Principles of ILO Convention No. 169, Case Study No. 7 (Geneva, International Labour Organization, 2008), pp. 19 and 56-57.

peoples are incidental and general (and not very meaningful), while others are more specific about the actual situation of indigenous persons with disabilities. Indigenous persons with disabilities are mentioned in the Committee's concluding observations for Argentina and Peru (CRPD/C/ARG/CO/1 and CRPD/C/PER/CO/1), with the Committee focusing mainly on statistics and education. Argentina was also requested to adopt specific policies and programmes for indigenous persons with disabilities under article 5 of the Convention, on equality and non-discrimination.

III. Perceptions of disability among indigenous peoples

18. Persons with disabilities are faced with attitudinal barriers in most societies, including stigma, fear, prejudice, low expectations, paternalism or failure to be informed. The Convention seeks to tackle those barriers. A key guiding principle of the Convention is found in its article 3, in which it is stated that disability is part of human diversity, meaning that it is no different from other features that distinguish one person from another.

19. In some indigenous languages, there is no translation of the term "persons with disabilities". Sometimes, there are terms that are pejorative or that cover only certain types of disability. In pre-colonial Maori culture, persons with disabilities may have been well supported and valued, but this support may have been withdrawn in harder times or if sickness or impairment was believed to be due to an infringement of sacred rules, an affliction from a supernatural being or ancestor, or spiritual powers, witchcraft or magic.[3] There are also indigenous languages that have used very positive terms for persons with certain disabilities, often linked to the fact that they were seen as having special gifts (i.e. from the creator). Each person has a special role in his or her community and impairment is seen as difference rather than deficiency.[6]

20. It also appears to be the case that, in several indigenous societies that previously had a more respectful attitude towards persons with disabilities, the impact of colonialism and the Western model of development may have led to a more negative attitude. This shift has often also been increased by the application of the now-outmoded medical model of disability, which has focused on what may be termed "correcting" the individual instead of taking a more holistic approach, as would also better reflect the earlier culture of indigenous peoples. In some places, the perception of what was once seen as a gift, a source of wisdom or a welcome contact with the spirits or the spiritual or philosophical life has changed because of the rupture of social systems resulting from a Western model of development. It is extremely important to strengthen indigenous institutions to regain or build this inclusion. Just as disability is an evolving concept, indigenous cultures and world views are also not static and can affect persons with disabilities positively or negatively.

[6] Jamie MacDougall, *Where the River Flows: Aboriginal People with Disability, A Literature Review: Focus on Employment*, Human Resources and Skills Canada, Aboriginal Affairs Directorate (October 2006), pp. 31 and 32.

IV. Key issues for indigenous persons with disabilities

A. Self-determination

21. The right of indigenous peoples to self-determination needs to be at the heart of any policy that seeks to promote and protect the rights of indigenous persons with disabilities. Indigenous persons with disabilities have the same right to benefit from self-determination as other members of indigenous peoples. Accordingly, this collective right must be taken into consideration in elaborating all policies and designing and delivering needed services. The right of indigenous peoples to determine their political or organizational systems should include and respect members with disabilities and should be exercised with the active participation of those members. An increased understanding of and concern for broader self-determination and jurisdictional issues is needed in this regard.[7]

22. The Convention seeks to provide to persons with disabilities the same rights as their peers without disabilities. This notion also applies to indigenous peoples. Indigenous persons with disabilities should benefit from the same rights and opportunities as other indigenous persons from their community.

B. Participation in decision-making and consultation

23. The right to participate in decision-making processes is protected in both the Convention and the Declaration. They contain articles on participating in life-affecting decisions (arts. 4 (3) and 29 of the Convention, in addition to art. 33 (3), and arts. 18 and 19 of the Declaration), the right to participate in political and public life (see, for example, art. 29 and preambular paragraph 7 of the Convention and arts. 5 and 11 of the Declaration). Article 20 of the Declaration states the right of indigenous peoples to maintain and develop their political, economic and social systems or institutions.

24. For indigenous persons with disabilities living outside their communities, it is important that general organizations of persons with disabilities include them as members, learn how to advocate on their behalf in a culturally appropriate way and exchange knowledge and experience.

25. There is scant evidence of the participation of indigenous persons with disabilities in consultation processes in place in their communities or States. The formation of organizations of persons with disabilities can be an important factor or step to facilitate consultation and meaningful participation in decision-making, as has been done in Australia (the First Peoples Disability Network) or in Nicaragua and Honduras, where Miskito divers with disabilities have formed organizations. Additional support for and consultations with such organizations are needed.

26. The level of inclusion of indigenous persons with disabilities in indigenous institutions has not yet been sufficiently examined and most available evidence is anecdotal. Some indigenous persons with disabilities do not participate in decision-

[7] According to evidence given by Wendall Nicholas, a member of the Maliseet nation at Tobique, to the Sub-Committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities of the Parliament of Canada, 19 March 2002.

making processes or community planning because of mobility limitations or because meetings are conducted in inaccessible places, depriving them of their right to political participation. Furthermore, indigenous persons with disabilities are often largely ignored and also lack the very basic means needed to participate. A recent study, for example, found that none of the Navajo Nation's public buildings was fully accessible to the estimated 40,000 persons with disabilities living on the Navajo Nation reservation.[8]

27. The Miskito people have two parliaments in the two autonomous regions of Nicaragua (Atlántico Norte, the capital of which is Puerto Cabezas, and Atlántico Sur, the capital of which is Bluefields), but without members with disabilities. The deputy mayor of Puerto Cabezas is a woman with a disability.

28. It is the responsibility of States at all levels and indigenous peoples to ensure that indigenous persons with disabilities are not discriminated against because of their disability. The right to participate in decision-making and consultations is fundamental to achieving this.

Political advocacy for inclusive development in the Brunca region in Costa Rica

Within the framework of the policy on human rights and equal opportunities for persons with disabilities of the Legislative Assembly of Costa Rica, a project is being undertaken that focuses on access to inclusive development for disadvantaged groups such as indigenous persons with disabilities, who number 14,000. Since 2007, work has been carried out to train indigenous leaders and representatives of organizations of persons with disabilities and public institutions in advocacy and social auditing in relation to the rights of persons with disabilities.

C. Discrimination (double/multiple discrimination)

29. Indigenous peoples face regular and systematic discrimination in many aspects of life. Discrimination experienced by persons with disabilities is very similar and takes diverse forms, including direct and indirect discrimination. This is why combating discrimination on the ground of disability is a main objective and central element of the Convention, similar to the non-discrimination provisions and rationale of the Declaration.

30. For indigenous persons with disabilities, a major issue is discrimination in the availability and quality of services as compared with other persons with disabilities, in addition to discrimination in their societies (being seen as lower than others) and lack of prioritization of their needs, unique capabilities and potential contributions to the development of their communities. Indigenous persons with disabilities may also experience the combined effect of discrimination against different aspects of their identities. For example, an indigenous child may be unable to attend school if

[8] A!ysa Landry, "Navajo Nation fails to provide disability access", *Daily Times* (Farmington, New Mexico), 28 December 2011. Available from http://www.daily-times.com/ci_19629734.

the facilities are not accessible and also if instruction is not available in his or her indigenous language.

D. Access to justice

31. Similar to the mistrust that indigenous peoples frequently have towards the formal justice system, the experience of persons with disabilities is also often negative, given that the justice system has been designed without consideration of their needs. Indigenous peoples who have their own traditional justice systems will need to ensure their accessibility to indigenous persons with disabilities. This would include, for example, ensuring that deaf indigenous persons can communicate in sign language, that the premises are accessible and that information is available in alternative formats.

32. There is a common experience of indigenous women and of women with disabilities that victims of rape are faced with indifference and inaction, often leading to non-reporting of these cases, or, in some instances, to forced marriage. There is a common experience of far-reaching impunity faced by indigenous peoples and persons with disabilities that puts them especially at risk of experiencing situations of violence. Furthermore, the general justice system needs to be accessible to persons with disabilities and also sensitive to indigenous persons with disabilities. Disability awareness training, with rights-based and intercultural approaches, needs to be provided to staff in charge of the administration of justice.

33. Indigenous peoples and persons with disabilities (in particular persons with intellectual and psychosocial disabilities) are usually overrepresented in correctional institutions and other types of detention centres, a situation that can be linked to the inaccessibility of justice. More research would be required into the specific situation of indigenous persons with disabilities in this specific context.

E. Education, language and culture

34. Article 24 of the Convention sets forth extensive obligations on education of persons with disabilities, while the Declaration contains a range of relevant articles and sets forth a dual approach mentioning the right of indigenous peoples to establish and have their own educational systems and institutions and culturally appropriate methods. It also provides that indigenous individuals, particularly children, have the right to all levels and forms of education of the State without discrimination. While indigenous children face challenges in gaining access to appropriate education in their communities, indigenous children with disabilities face further barriers.

35. Specifically, there is a lack of prioritization of education of children with disabilities by their parents, resulting from the lack of awareness of and support by States. Although there is a lack of empirical data, anecdotal evidence suggests that a disproportionately high number of indigenous children with disabilities may be out of school altogether. In New Zealand, in 2006, 42 per cent of Maori persons with disabilities had no educational qualifications, compared with 34 per cent of non-Maori persons with disabilities.[3] It may also be the case that, when indigenous children with disabilities are able to gain access to education, special education is the main option.

36. The Convention clearly establishes that all children with disabilities have the right to be part of the general education system, requiring that children with disabilities be provided with the necessary reasonable accommodation. For indigenous children with disabilities who live in their communities, this means that the indigenous education system must provide them with the required support.

Sign languages

Sign languages are languages in their own right and, in some countries, have been recognized in the national constitution or other legislation as an official national language. Sign languages and linguistic rights are protected in the Convention. Signed language has been documented at least among North American, South American and Australian indigenous peoples.[a] Signed language was used in varying degrees as an independent communication method within most language families indigenous to North America. There is a difference between signed language used as alternative communication by hearing persons and that used by deaf people as a first language in deaf communities, which are separate languages in themselves. In some places, both deaf and hearing indigenous persons have used signed language. For some deaf persons around the world today, the primary means of communication are home signs, which have been described as signs developed when deaf persons are isolated from other deaf persons and need to communicate with hearing people around them. Home signs are the primary means of communication of deaf indigenous peoples in Australia, where there is a lack of consultation with indigenous deaf persons on their language preferences. Several North American indigenous peoples incorporate traditional signed language into their language and education programmes. Contact with a larger sign language or the spreading out of the deaf community can lead to the endangerment or loss of traditional sign language. Sign languages are also usually not included in work on endangered languages.

[a] See Jeffrey Davis, "Evidence of a historical signed lingua franca among North American Indians", *Deaf Worlds*, vol. 21, No. 3 (2005), pp. 47-72.

F. Access to health

37. Disability has often been incorrectly seen as mainly a health issue. The right to health is one of the many rights mentioned in the Convention, but it is not more relevant than the rights to education, participation in public and political life or employment, to cite just a few. Nevertheless, the *World Report on Disability* highlights that persons with disabilities face serious challenges in gaining access to health services, leading to decreased life expectancy. This includes both disability-related health issues and health issues not so related. The *State of the World's Indigenous Peoples* report highlights that indigenous peoples have a lower level of access to health and greater unmet needs than the general population, meaning that their health outcomes and life expectancies are poorer.

38. In the design of intercultural health systems, it will be important to ensure that full (physical and communicational) accessibility to persons with disabilities is part of that design, consistent with the prerequisite that these systems respect human rights as codified in international human rights instruments and international law. Furthermore, the right to self-determination with regard to health implies creating conditions for the full and effective participation of indigenous peoples in the design and management of health systems, which will require adequate attention to be paid to the situation of indigenous persons with disabilities. The commitment to building the human resources necessary for the participation of indigenous peoples in health policy and management, in addition to training non-indigenous health professionals in the cultures and languages of indigenous peoples, should also encompass disability awareness training, including the issue of how to obtain prior and informed consent for any health intervention. The right to health must be linked not only to the recognition of the cultural, ethnic and linguistic diversity of indigenous peoples but also to the right to live in healthy habitats and to land rights.

39. Article 26 of the Convention, on habilitation and rehabilitation, while including health-related rehabilitation, goes well beyond health services. The article stresses that habilitation and rehabilitation are voluntary and indicates that they should be provided at the community level, a concept that is known in the disability community as community-based rehabilitation. In the specific context of indigenous peoples, article 26 should lead to community-based rehabilitation initiatives that promote the participation and inclusion of indigenous persons with disabilities and that are designed in a culturally appropriate way by indigenous peoples with the active involvement of indigenous persons with disabilities.

Intergenerational trauma

Indigenous peoples throughout the world suffer from intergenerational or historical trauma resulting from forced assimilation and displacement. Psychosocial disabilities and unresolved grief also resulted from the removal of children removed from their parents and their subsequent institutionalization. In addition, indigenous peoples were often removed from their lands and placed on to missions or reservations. In Canada, some 150,000 aboriginal children were removed and separated from their families and communities to attend residential schools. Two primary objectives of the residential schools system were to remove and isolate children from the influence of their homes, families, traditions and cultures and to assimilate them into the dominant culture. While most Indian residential schools ceased to operate by the mid-1970s, the last federally run school closed in 1997 and it was only in 2010 that Canada announced that it would repeal the parts of the Indian Act that allowed for the establishment of the schools. Advocates were eventually able to achieve a settlement, an apology and a truth and reconciliation commission. As part of the settlement, some mental health and healing services are being made available to survivors.

In the United States of America, native children were put in boarding schools from 1869 to the 1960s where, in addition to the traumas associated with forced separation from their families and forced assimilation, many experienced physical and sexual abuse. The mental health side of such

history and abuse is not always well known. In Australia, abuse and neglect in institutions were reported. Post-traumatic stress disorder and anxiety were also some health consequences identified by indigenous persons with disabilities, but are not widely known. A residual and legitimate fear of assessment on the part of indigenous persons with disabilities in some communities appears to pose a major challenge, which can be mitigated by training, the involvement of indigenous peoples as key workers and additional steps to address past wrongs.

G. Adequate standard of living

40. Many indigenous persons with disabilities live in poverty and, in some cases, because of a development model that causes poverty. There is a vicious cycle of disability and poverty. For indigenous persons with disabilities, the situation is worse. Living in mainly rural areas also has a significant impact on poverty and persons with disabilities. They often lack the basics such as food, clothing, sanitation, support for the basic necessities of life, assistive devices, mobility aids and health and rehabilitation services. Also lacking are clinics, disability skills training and disability workers, in addition to employment programmes, job skills training and transition to employment programmes, often resulting in indigenous persons with disabilities lacking the skills required to earn a living.

41. Often, indigenous persons with disabilities are unaware or do not avail themselves of disability support pensions available to persons with disabilities. For indigenous persons with physical disabilities, there are usually many obstacles to moving around in the environment of their communities, leading to dependence and poverty. Even when technical aids are available, moving around in a wheelchair is mostly impossible, resulting in people either remaining in their homes or being forced to leave their community to move to urban settings. Individual autonomy, however, is a general principle of the Convention (para. (n) of the preamble and art. 3) and is closely related to the rights to liberty and security of the person and personal mobility, among others. More efforts need to be made to ensure equal access to land, natural resources and capital for indigenous persons with disabilities, paying special attention to indigenous women with disabilities.

H. Living in the community

42. Article 19 of the Convention guarantees the right of persons with disabilities to live independently and be included in the community. In many countries, there is a widespread lack of State action to provide services and support in the community that are designed in consultation with persons with disabilities, often resulting in the bad practices of State and private institutionalization of persons with disabilities.

43. While there are jurisdictional and user consultation issues relating to service provision for many persons with disabilities around the world, the contexts are even more specific for indigenous peoples. The different relationship with State services and jurisdictional and cultural issues play key roles. Where there are State services available to indigenous persons with disabilities, service providers rarely include

indigenous professionals who would have the same cultural understanding as an indigenous person with disabilities.[9] Non-indigenous providers may lack training in or awareness of relevant cultural approaches or issues. There is also a lack of support or services within many indigenous communities. Support available to indigenous persons with disabilities must therefore be analysed both for its compliance with the Convention and its respect for indigenous cultures, institutions and organizations.

44. In some cases, indigenous persons with disabilities, owing to the lack of adequate support services in their community, live in group home settings, far away from their communities, where they are not supported to participate in community events and where staff are not supported to develop culturally competent skills to facilitate such participation. The repercussions of previous practices of separation from their communities continue to affect many indigenous persons with disabilities today, whether directly or indirectly. Indigenous persons with disabilities in New South Wales, Australia, have expressed fear that living in Government-owned or Government-run accommodation, away from their families and communities, is akin to the historical removal of Aboriginal people from their communities.[10]

45. Public resources need to be allocated by States at the community and organization levels to build the capacity of indigenous peoples so that they can implement the Convention in a culturally appropriate way. States should provide resources for capacity-building and the development of such new initiatives.

I. Indigenous children with disabilities

46. There is much evidence that the lack of support and services for families with indigenous children with disabilities has led to the displacement of families from their communities and often even to the separation of children from their families and communities. In many societies in which indigenous peoples suffer the intergenerational trauma caused by, among other things, forced assimilation and the removal of children from their families, indigenous children with disabilities continue to be at a high risk of being separated from their families and placed in institutions or with non-indigenous families.

47. Support services for indigenous families with children with disabilities need to be designed in a culturally sensitive way and particular attention will need to be paid to avoiding the use of an approach that might replicate, to some extent, past practices that have created traumas. This will also comply with the principle of best interest of the child, as indicated in the Convention on the Rights of the Child and reiterated in the Convention on the Rights of Persons with Disabilities.

48. Articles 7 and 10 of the Convention on the Rights of Persons with Disabilities protect the right to life of children with disabilities. Customs must be respected but only insofar as they do not violate international human rights law, meaning that any practices of infanticide of children with disabilities would be contrary to those

[9] National Council on Disability, *Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide* (Washington, D.C., 2003).

[10] Aboriginal Disability Network, New South Wales, *Telling it like it is: a report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004-2005* (Sydney, 2007).

provisions and other international human rights law.[11] Article 18 of the Convention mandates States to ensure that all children with disabilities are registered at birth. There is some evidence that children with disabilities, including indigenous children with disabilities, are overrepresented among non-registered children. Increasingly, indigenous institutions are officially recognized to have the responsibility of birth registration. It must be ensured that such institutions do not discriminate against children with disabilities.

Indigenous-led service delivery systems

In some places, such as North America, there are efforts to have indigenous-led service delivery systems. In Canada, First Nations indigenous persons with disabilities in Manitoba and their allies proposed a service delivery model that was discussed at an All Chiefs Assembly in Manitoba in 2007. It identified that the Government should provide adequate services and funding to have a service delivery system driven and controlled by the First Nations that would then be more balanced and equal for children. The model entails a First Nations disability resources centre, regional centres, mobile therapy units, community-based support, resources and equipment, and training and capacity-building for the First Nations in cooperation with local universities. It entails a phased approach, gradually increasing delivery by the First Nations as they gain the necessary resources and capacity. For indigenous children in these communities and their families, the new system would make a specific difference in their lives and in the life of the community. Indigenous children with disabilities would not have to leave their home or be separated from their families to gain access to services, but instead can be part of their families, maintain their culture and, especially for those in the north, maintain their language. Currently, it remains a model plan and has not yet been implemented.

J. Indigenous women with disabilities

49. Available evidence shows that girls and women with disabilities are at higher risk of violence than girls and women without disabilities (see A/HRC/20/5) and that indigenous women are disproportionately victims of sexual violence.[12] Violence against girls and women with disabilities happens at home, but also in schools, residential institutions and in disability services. The definition of "violence" is broad and includes specific forms of violence against women with disabilities. Articles 14 to 17 and 25 of the Convention mandate States to have policies in place to tackle this problem.

50. The situation of indigenous women with disabilities varies between communities. Indigenous women with disabilities experience challenges that other indigenous women also face, such as lack of representation in government, including in

[11] Henriksen, "Key principles", p. 57.

[12] Amnesty International, *Maze of Injustice* (New York, 2007).

indigenous parliaments; lack of good hospital networks; lack of consultation; multiple forms of discrimination; poor access to education, health care and ancestral lands; high rates of poverty; and increased risk of violence and sexual abuse, including trafficking. Empowerment of indigenous women is sometimes portrayed as an imposition of Western values. Indigenous women with disabilities often experience additional discrimination, such as more restrictions on their legal capacity and lack of an accessible legal system.

51. As with other women with disabilities, some indigenous women with disabilities are not seen as capable of raising children and there are barriers to marriage. A number of studies have shown that indigenous women and women with disabilities are at particular risk of involuntary sterilization programmes as an instrument of population control, often inspired by eugenics. To be effective, all policies and measures targeting indigenous women and girls with disabilities need to be designed in a culturally appropriate way.

K. Emergency situations and disaster risk reduction

52. Article 11 of the Convention highlights that persons with disabilities are especially vulnerable and must be assisted and protected in situations of natural and human-caused emergencies. The risk of exposure of indigenous persons with disabilities to such emergencies may be elevated because indigenous peoples often live in areas of special risk relating to climate change (Africa, coastal zones, the Pacific and the Arctic), militarization and armed conflict and the impact of extractive industries.

53. Initiatives that seek to make indigenous peoples more resilient to such challenges need to be undertaken in a manner that is inclusive of disability and fully participatory.[13] Protocols that are to be established, including those that foresee the displacement of the community, need to encompass actions targeting and involving indigenous persons with disabilities. Any resettlement must have the full, free, prior and informed consent of indigenous peoples or, in the case of natural disaster or other emergency, be inclusive of disability. Similarly, all emergency and disaster risk reduction efforts should address the situation of indigenous persons with disabilities. In this regard, the Hyogo Framework for Action, which refers to the "disabled", states clearly that the information should incorporate relevant traditional and indigenous knowledge and cultural heritage and be tailored to different target audiences, taking into account cultural and social factors.

V. Conclusions

54. The available information on indigenous persons with disabilities shows a serious gap in the implementation and enjoyment of a wide range of rights, ranging from self-determination and individual autonomy to access to justice, education, language, culture and integrity of the person. There are significant unmet needs and

[13] See, in this regard, annex 3 to the Yogyakarta Declaration on Disaster Risk Reduction in Asia and the Pacific 2012, adopted at the fifth Asian Ministerial Conference on Disaster Risk Reduction, held in October 2012 in Yogyakarta, Indonesia, which contains a statement of individuals and organizations concerned with disability.

rights that are not being addressed, of which gaps in access to health, life expectancy, educational qualifications, income, safety of the person and participation in decision-making are just a few examples.

55. Urgent action is required by Member States, the United Nations, indigenous peoples, indigenous peoples' organizations and organizations of persons with disabilities, among others. They must take immediate steps to improve the situation of indigenous persons with disabilities, to consult them, to enable them to be heard and to ensure that they are empowered to claim their rights as set forth in the two main legal standards, the Convention on the Rights of Persons with Disabilities and the United Nations Declaration on the Rights of Indigenous Peoples, for which there exist major implementation gaps for this group. More attention, including research, needs to be paid to this group by all stakeholders, in particular indigenous peoples and organizations of persons with disabilities. States need to allocate public resources at the community and organization levels to build the capacity of indigenous peoples so that they can implement the Convention in a culturally appropriate way. For policies and services to be culturally sensitive and relevant, indigenous persons with disabilities must be involved in their design. The unique experiences and knowledge of indigenous persons with disabilities must be universally respected.

VI. Recommendations

A. Main recommendations

56. Relevant United Nations agencies dealing with indigenous peoples' issues should take action on the inclusion of indigenous persons with disabilities in all their activities, make their websites accessible to persons with disabilities, promote increased participation of indigenous persons with disabilities in their annual sessions and consider having expert sessions on indigenous persons with disabilities.

57. The President of the General Assembly should ensure that the high-level meeting on disability and development, to be held in 2013, and the World Conference on Indigenous Peoples, to be held in 2014, in addition to their preparatory processes, are inclusive of and accessible to indigenous persons with disabilities and take place with their full and effective participation. The President should also ensure that their views and interests are reflected in the agenda and the background papers of the meetings.

58. Indigenous organizations should become more proactively inclusive of indigenous persons with disabilities by ensuring a barrier-free environment and by recognizing the existence of indigenous persons with disabilities and their value as full members of indigenous peoples.

59. Organizations of persons with disabilities should include the perspectives, voices and participation of indigenous persons with disabilities.

60. United Nations entities, including the United Nations Development Programme, the United Nations Children's Fund, the United Nations Entity for Gender Equality and the Empowerment of Women, the United Nations Population Fund, the World Health Organization, the United Nations International Strategy for Disaster Reduction and the regional commissions, should include indigenous persons with disabilities in their work so as to support the establishment and develop the capacity

of organizations of indigenous persons with disabilities. They should specifically report on their work in these areas in their dialogues with the Permanent Forum on Indigenous Issues.

61. States should include information on the rights of indigenous persons with disabilities when they submit reports to the Permanent Forum, the Committee on the Rights of Persons with Disabilities, other relevant treaty bodies and the Working Group on the Universal Periodic Review. States should allocate funding to build the capacity of indigenous peoples to provide culturally adequate services and for the establishment and development of the capacity of organizations of indigenous persons with disabilities, including a focus on indigenous women with disabilities.

62. States should further support the participation of indigenous persons with disabilities in consultations regarding the post-2015 development agenda and ensure that their needs and perspectives are included in the resulting framework.

B. Other relevant recommendations

Recommendations to indigenous peoples

63. Indigenous peoples should include indigenous persons with disabilities who are familiar with their own rights in their teams negotiating the standards currently being elaborated by the Organization of American States.

Recommendations to States

64. States should help to guarantee the right to life of indigenous persons with disabilities by ensuring that children with disabilities are registered at birth and take measures to prevent infanticide of children with disabilities.

65. States should make sign language education available for deaf indigenous persons with disabilities and respect relevant cultural rights in the Convention and the Declaration. They should consult deaf indigenous persons on their issues, needs and preferences. They should pay attention to the unique contribution that deaf indigenous persons make to the cultural heritage of indigenous peoples and of the world.

66. States should create high-level Government task forces that meaningfully include persons with disabilities, indigenous peoples and their representative organizations to review existing Government programmes and policies and to prepare comprehensive plans for the implementation of the Convention and the Declaration, respectively.

67. State donors and development partners are encouraged to implement article 32 of the Convention inclusively of indigenous persons with disabilities.

Recommendations to the United Nations system

68. The special rapporteurs on the rights of indigenous peoples and on disability should include meetings with indigenous persons with disabilities in their country visits and request the United Nations country team and others providing support in the organization of meetings with Governments and civil society to ensure that meetings take place in venues accessible to persons with disabilities.

69. The Department of Economic and Social Affairs should prepare a series of briefing notes relating to the rights of indigenous persons with disabilities, similar to the work that has been carried out to mainstream gender in the Permanent Forum, and a publication that identifies synergies and complementarity of obligations and implementation. All this work should be performed in cooperation with persons with disabilities and indigenous peoples and their representative organizations.

70. The Department of Economic and Social Affairs should work with Member States and relevant United Nations bodies, including the regional commissions, to improve the collection and dissemination of disaggregated data, statistics (as required by article 31 of the Convention), information and knowledge regarding the situation of indigenous persons with disabilities, in addition to the use of that information.

71. The Inter-Agency Support Group on Indigenous Issues and the Committee on the Rights of Persons with Disabilities should explore synergies and opportunities to advance their work in relation to indigenous persons with disabilities, including through the use of the United Nations Development Group Guidelines on Indigenous Peoples' Issues and the guidance note on integrating the rights of persons with disabilities in United Nations programming at the country level.

72. The Expert Mechanism on the Rights of Indigenous Peoples should include the rights of indigenous persons with disabilities in its work as a cross-cutting issue, consistent with the Convention and the Declaration, support efforts to make the voices of indigenous persons with disabilities heard and consult indigenous persons with disabilities and their representative organizations in the preparation of studies.

73. The Committee on the Rights of Persons with Disabilities should consider making recommendations to States parties to the Convention concerning the situation of indigenous persons with disabilities.

74. Relevant United Nations mechanisms and funds, including the United Nations Partnership to Promote the Rights of Persons with Disabilities, the multi-donor trust fund of the United Nations-Indigenous Peoples' Partnership and the Indigenous Women's Fund of the International Indigenous Women's Forum, should include indigenous persons with disabilities in projects at the country level in cooperation with indigenous persons and women with disabilities and their representative organizations.

75. The International Labour Organization should step up its work to advance the rights of indigenous persons with disabilities, in keeping with Convention No. 169, including with regard to submission of country reports on implementation of the Convention, in addition to the Convention on the Rights of Persons with Disabilities and the Declaration, and ensure that indigenous persons with disabilities are included in efforts to implement the new International Labour Organization recommendation on national floors of social protection.

76. The Office of the United Nations High Commissioner for Human Rights should ensure the accessibility for persons with disabilities of the reports of the Special Rapporteur on the rights of indigenous peoples, the Expert Mechanism and related websites, in line with relevant standards such as the Web Accessibility Initiative Web Content Accessibility Guidelines, in cooperation with United Nations-wide initiatives to improve the accessibility of reports and websites.

77. The Office of the United Nations High Commissioner for Human Rights should proactively reach out to indigenous persons with disabilities and encourage their participation in its Indigenous Fellowship Programme.